Parenting Post-Secondary Students with Disabilities: Becoming the Mentor, Advocate, and Guide Your Young Adult Needs

National Center on Secondary Education and Transition

The importance of involving parents in the education of elementary and secondary school students is widely encouraged. In fact, federal law - the Individuals with Disabilities Education Act (IDEA) - has created a process to involve parents in the education of their children with disabilities. Once youth with disabilities graduate from high school, however, resources and guidance to help parents with this challenging new phase of parenting become difficult to find. Yet, parents continue to be important role models and guides for their young adult sons and daughters. For students with disabilities, parents may be a key part of the support network they need to succeed in the postsecondary environment. Experts on human development consider late adolescence a very important time of life for all individuals. It is a "launching period" when parents help youth develop the skills they will need as adults. This "launching" process does not end because a student graduates from high school, reaches the legal age of adulthood ("age-of-majority"), or enrolls in a college or other training program. New and important parenting issues continue to arise as young adults grow up.

Parents as Mentors

Although parents of young adults with disabilities no longer have the same authority they once had in the lives of their children, they can provide guidance and support through a mentor or advisor role. Mentors teach, challenge, and support their protégé. A parent's mentoring relationship must be based on an underlying trust and respect for one's child as someone capable of learning how to manage his or her own life. Whether a student has a disability or not, the greatest challenge for parents of postsecondary students is learning when and how to be supportive while still encouraging self-determination - and independence. It may require a giant leap of faith for parents to trust that their sons and daughters have all the resources they need to deal with the unfamiliar challenges of postsecondary - education. Nonetheless. postsecondary schools students as legal adults. It is important for parents to do all they can to reinforce their faith

in their child's ability to manage life at school. Effective mentoring takes clear communication skills. Parents may find it helpful to learn about and practice these skills so they can use this technique consistently and well. This approach is explored in depth in the book "Don't Tell Me What to Do - Just Send Money": The Essential Parenting Guide to the College Years by Helen E. Johnson and Christine Schelhas-Miller.

Parents as Advocates

No matter how much parents respect and trust their children, it is difficult to let them learn from mistakes when the consequences are serious. Although parents must be careful not to "take over" the problems of their young adult sons and daughters, situations may arise when parents need to take a more active role.

Young adults often unload everyday worries on parents and then go on about their lives. Parents must distinguish between these kinds of situations and more serious circumstances such as substance abuse, mental or physical illness, other threats to their child's health or safety, serious financial issues, and, for youth with disabilities, discrimination.

parents decide to act, their first involvement should always be directly with their son or daughter - to whom parents can provide resources, information, and emotional support. Parents may also want to contact the postsecondary program to ask for help assessing the situation. If the child is in college, the Disability Services Offices is a good place to start. Other offices may also be appropriate depending on the nature of the concern. These include health services. the Dean of Students. ADA coordinators, and Section 504 coordinators. Many colleges and universities also have a parents' program office.

Parents of students with disabilities who are concerned about their child's educational program or academic accommodations can draw on their experience as special education advocates. However, they will need to understand the differences between special

education laws, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act. Parents may encounter some resistance to their involvement. Postsecondary professionals are not used to working with parents and may see it as inappropriate or even harmful. In fact, school staff cannot legally share information with parents without a student's written permission.

Young adults of legal age are responsible for making their own decisions even in serious situations. Unless parents are the legal guardians of their adult child, their role is to support their son or daughter as the young adult solves his or her problems. Parents may only need to help them gather information and understand their options. Ultimately, a student's maturity, cultural values, and other individual characteristics will determine the kind of involvement and family support that is appropriate and helpful for each student.

So What's a Parent to Do?

The post-secondary years provide students with both new freedoms and new responsibilities. Many students are living away from home for the first time or are new to making personal decisions on their own. Parents are naturally concerned about the safety, health, and social adjustment of their sons and daughters. Disability-related issues can make this an even more challenging time for students and parents. However, there is help available.

Materials for parents of college students, such as the previously mentioned book by Helen E. Johnson and Christine Schelhas-Miller, can be

found on the shelves of local bookstores and libraries. Several Web sites have also been created for the parents of college students. Many colleges and universities, for example, provide tips for parents on their Web sites. Unfortunately, these resources do not address the many unique challenges faced by students with disabilities and their families.

Information developed specifically for the parents of high school students with disabilities, on the other hand, does not cover parenting issues during the college years. These materials generally try to help parents prepare youth for the transition to post-secondary education, find financial aid, and learn about the ADA and Section 504. The benefits of family support may be mentioned, but what this support looks like at the post-secondary level is not described. In fact, an emphasis in recent transition literature overprotective parenting and helplessness has given some parents and educators the mistaken impression that parent involvement is wholly undesirable at the postsecondary level.

Although not widely available, a handful of recent studies confirm the value of the supports parents provide at the post-secondary level and indicate that active parent involvement can foster, rather than hinder, self-determination. Additional studies - and research-based guidance on these issues is needed to help parents effectively support their sons and daughters with disabilities in the post-secondary years.

Resources for Parents

Visit the PACER Center (<u>www.pacer.org</u>) or National Center on Secondary Education and Transition Web sites for more online resources that can help parents of post-secondary youth with disabilities.

Harris, M.B., & Jones, S.L. (1996). The Parent's Crash Course in Career Planning: Helping Your College Student Succeed. VGM Career Horizons.

Johnson, H.E., & Schelhas-Miller, S. (2000). Don't Tell Me What to Do, Just Send Money - The Essential Parenting Guide to the College Years. St.Martin's Griffin.

Newman, B.M., & Newman, P.R. (1992). When Kids Go to College: A Parent's Guide to Changing Relationships. Ohio State University Press.

Additional Resources

Web Sites with further information on both disability and non-disability related post-secondary issues:

- PACER Center, http://www.pacer.org
- National Center on Secondary Education and Transition, http://ici.umn.edu/ncset/
- National Center for the Study of Postsecondary Education Supports, http://www.rrtc.hawaii.edu/
- HEATH Resource Center, http://www.heath.gwu.edu/
- National Information Center for Children and Youth with Disabilities, http://www.nichcy.org/
- "Understanding the Transition to College," (George Washington University site): http://gwired.gwu.edu/counsel/html/parent-services.html
- College Parents of America, http://www.collegeparents.org/
- ParentsAssociation.com, "College Central", http://www.parentsassociation.com/college/index.html
- Higher Education Center for Alcohol and Other Drug Prevention, http://www.edc.org/hec/parents/

For individualized information, advocacy and referral services contact your nearest Parent Information and Training Center or Center for Independent Living:

- Parent Information and Training Centers, http://www.taalliance.org/PTIs.htm
- Centers for Independent Living, http://www.virtualcil.net/cils/

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